

Summary of Veteran Engagement Sessions

Presented to GWVI RAC

22 September 2022

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Veteran Engagement Session #6

- April 6-7, 2022
- Virtual
- Total attendance= 243
- Talking Points:
 - Health concerns
 - Research issues
 - Quality of Life
 - What do you want the Secretary of VA to know?

Veteran Engagement Session #7

- July 20-21, 2022
- Virtual
- Total Attendance= 909

- Section 1:
 - What health problems concern you most about the 1990-91 Gulf War?
 - What treatments have helped you manage your Gulf War health problems
- Section 2:
 - What aspect of your Gulf War illness most affects your quality of life?
 - What helps you most to manage these interferences?
- Section 3:
 - If you could tell the VA Secretary one thing about being a Gulf War Veteran with Gulf War illness, what would it be?

Section 1: What health problems concern you most about the 1990-91 Gulf War? What treatments have helped you manage your GW health problems? Led by Dr. Drew Helmer.

Problem/Symptom	Treatment
Sensitivity to ultraviolet/sunlight	Avoiding sunlight
Migraines/headaches	Avoiding triggers (smells), diet modification (no gluten, sugar, alcohol), pharmaceuticals, Botox injections
Dysautonomia	Recognizing and avoiding triggers, no smoking/drinking
Cancer, specifically cancers affecting women	None stated
Irritable Bowel Syndrome (IBS), chronic fatigue, fibromyalgia	Positive mental attitude, exercise as able, staying mentally active.
IBS, muscle pain, brain fog, PTSD, bladder/urinary issues	Medical and pharmaceutical intervention for IBS and bladder/urinary issues
Cardiovascular issues/amputations	Medical intervention
Dermatological and neurological issues	None stated
PTSD, IBS, dermatological issues, memory loss, central nervous system issues	None stated
Crystalline silica exposure causing respiratory issues, autoimmune disorders	None stated
Toxic exposures (oil) causing GWI health issues	None stated
Early onset prostate cancer, PTSD	Vagal nerve stimulator for pain and PTSD management
Respiratory issues, gastro-intestinal (GI) disorder	Neti pot, inhalers, over-the-counter (OTC) medications
Neurological issues, degenerative nerve disease, chronic pain, depression	Crisis Line for depression issue helped Veteran to find mental health and pain management groups

Section 2: What aspect of your GWI most affects your quality of life? What helps you most to manage these interferences? Led by Jane Wasvick.

Problem/Symptom	Treatment
Cognitive, similar to Parkinson's disease and dementia	Self-management
Cognitive, memory loss issues	None stated
Chronic pain and fatigue	Self-management
Premature aging	None stated
Muscular—pain, weakness, exercise intolerance	Using water to relax muscles, showers, water jets, scuba diving. The use of hyperbaric chamber therapy
Mental health/cognitive decline	Positive mental attitude/helping others
GWI in general	Staying mentally positive, exercise (mental and physical), being socially active
Birth defects caused by GWI	None stated
Respiratory/asthma	Participating in GWI clinical research studies; staying mentally positive
Dermatological and GI disorders	None stated
Dermatological disorder	Stays mentally positive, and being mentally and physically active; to not dwell on his problems
Chronic pain and cardiovascular issues	None stated
Migraines	Botox, vitamins

Section 3: If you could tell the VA Secretary one thing about being a Gulf War Veteran with Gulf War Illness, what would it be?

Led by Barbara Ward (day 1) and Col. Richard Gaard (day 2).

- For the VA to do meaningful/translational research on GWI and to better treat GWV.
- The VA needs to establish toxic exposures specialty clinics.
- The VA needs a continuity of care; all VA clinics should be the same, not different levels of care depending on location.
- The VA needs to address reproductive issues (male and female) and rebuild trust with GWV.
- The VA needs to improve neurological care, perhaps establish specialty clinics.
- When will Veterans be compensated for things that should have been automatically considered a presumptive condition.
- For the VA to research medical cannabis.

GWVI RAC Session – Qualitative Chat Coding

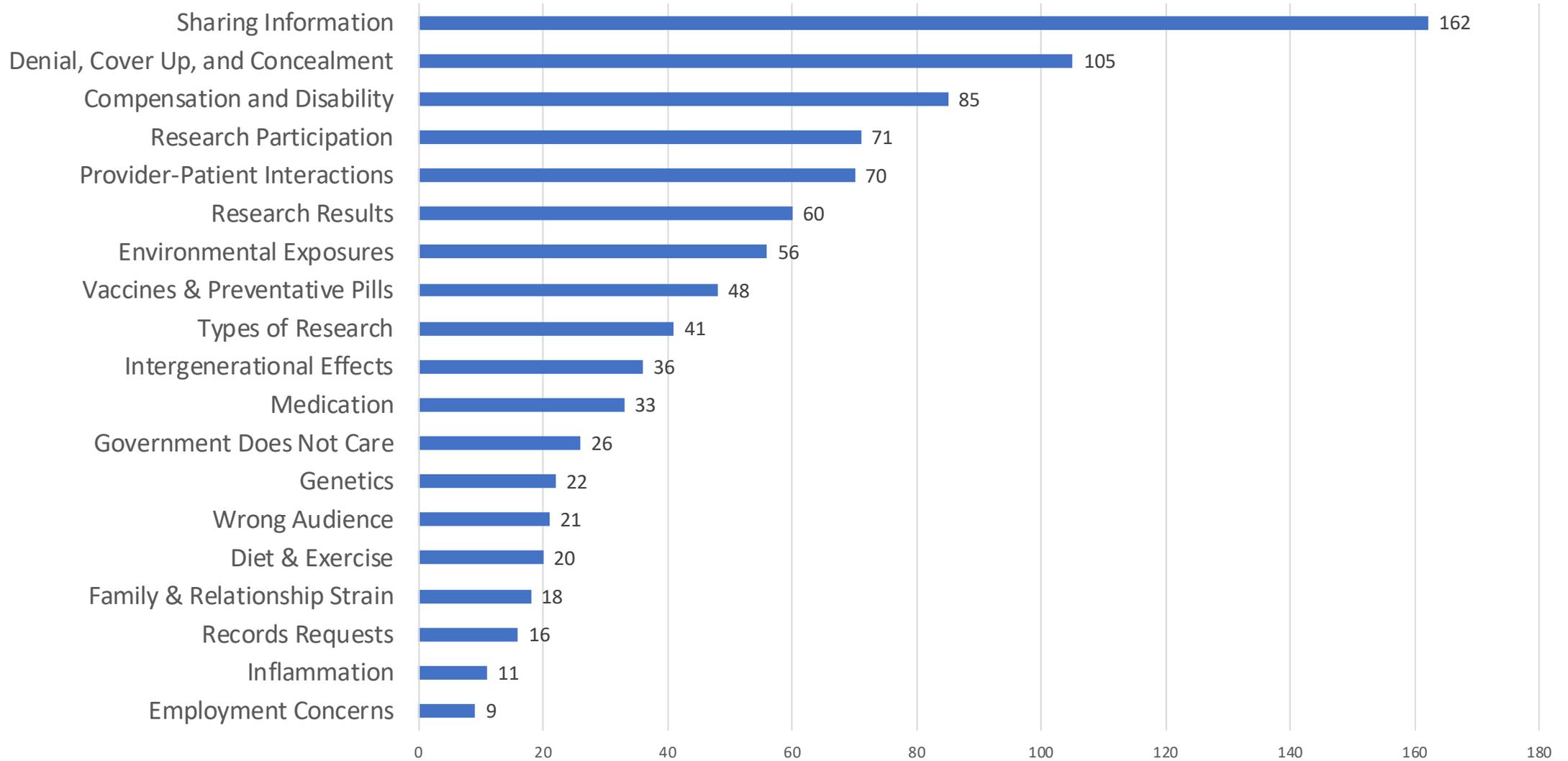
Gulf War Veterans Illnesses Research
Advisory Committee Meeting

January 27, 2022
(Virtual)

This was a full meeting of the
committee with scientific presentations.

- Analysis team:
 - Fletcher Sidle (Coder)
 - Rachele Lipsky, PhD (Coder)
 - Trenton Haltom, PhD (Methodologist)
- Length of chat: 6 hours
- Active chatters: 154
- Messages present: 1,486
 - All messages were coded
- Developed a codebook of 22 unique categories
- Applied codes: 1,744
 - Coding was not mutually exclusive: multiple codes could have been applied to one chat comment.

GWVI RAC Session Chat Coding Overview



Conclusion:

Veteran engagement sessions continue to be valuable forums for hearing the concerns of Gulf War Veterans and generating ideas for discussion at the full committee meetings.

Analysis of GWVI RAC chat messages can provide similar insight into Gulf War Veterans' concerns.